

The Unrepresented Patient: Where Institutional and Clinical Ethics Meet

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Loma Linda University Health



Conflicts of Interest Statement

- Grace Oei, MD, MA
 - No conflicts to declare
- Gerald Winslow, PhD
 - No conflicts to declare
- Gina Mohr, MD
 - No conflicts to declare



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Objectives

- Describe the different ways patients can be unrepresented
- Illustrate the moral and ethical difficulties that can occur when institutions make healthcare decisions for their patients
- Evaluate the effect of a systemic policy on the individual patient before and after implementation



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Acknowledgements

- Christian Johnston, JD
 - Associate General Counsel, Loma Linda University Health



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Who is the Unrepresented Patient?

It is a patient who:

- Does not have decision making capacity
- Does not have a surrogate decision maker



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Who is the Unrepresented Patient?

Ms. Paul

- 69 year old female with extensive past medical history including coronary artery disease, hypertension, arrhythmia, morbid obesity, diabetes mellitus, and moderate to severe chronic obstructive pulmonary disease, lived in a skilled nursing facility
- Admitted for treatment of a skin infection → severe sepsis
- Ms. Paul agreed to intubation and mechanical ventilation



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Who is the Unrepresented Patient?

Ms. Paul

- Will need long term mechanical ventilation to survive
- Friend requests that the team change status to DNAR and withdraw support and mentions an estranged son
- POLST requests Attempt Resuscitation and Full Treatment
- Team requests ethics consult



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Unrepresented Patient Needs

- Can friends make medical decisions for patients?
- Should the medical team try to find contact information for the estranged son for medical decision making?



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Who is the Unrepresented Patient?

Mr. Kenney

- 85 year old male with past medical history of hypertension, ischemic cardiomyopathy, diabetes mellitus, chronic kidney disease, and atrial fibrillation who lives at a skilled nursing facility
- Brought into the ED for a change in mental status and enlarging right neck mass



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Who is the Unrepresented Patient?

Mr. Kenney

- Previously hospitalized at our institution last month
 - Recommended outpatient biopsy for neck mass
- Tissue biopsy was not done
- Neck mass now quite large with purulent drainage



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Who is the Unrepresented Patient?

Mr. Kenney

- Neck mass biopsy → poorly differentiated squamous cell carcinoma
 - Unresectable per ENT
- Does not have decision making capacity
- No family or friends, no advance directive, no POLST, no durable power of attorney for health care
- Ethics consult requested



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Unrepresented Patient Needs

- Can friends make medical decisions for patients?
- Should the medical team try to find contact information for the estranged son for medical decision making?
- What constitutes an adequate search for a surrogate decision maker?
- Is a surrogate only needed to provide consent or is a surrogate needed to direct (“non-consentable”) medical care?
- Who should direct the course of medical treatment? Should it include withdrawal of life sustaining treatment?



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State & Citation	General Type of Statute	Can Patient orally name a Surrogate?	Priority of Surrogates (in absence of an appointed agent, surrogate, or guardian with health powers)	Limitations on Types of Decisions	Provides Standard for Decision-Making	Disagreement Process Among Equal Priority Surrogates
5. CALIFORNIA Cal. Probate Code §§4711 – 4727 (West 2017) Specifically, see §4711	Comprehensive Health Care Decisions Act	Yes §4623 and §4711	Only orally designated surrogate	For orally designated surrogate: Effective “only during the course of treatment or illness or during the stay in the health care institution when the designation is made, or for 60 days, whichever period is shorter.” N/A to civil commitment, electro-convulsive therapy, psychosurgery, sterilization, and abortion.	Yes §4714	N/A since designated surrogate is presumably one person
Cal. Health & Safety Code §24178 (West 2017)	Specialized provision applicable only to medical research		<ul style="list-style-type: none"> ▪ Spouse ▪ Domestic partner ▪ Adult child ▪ Custodial parent ▪ Adult sibling ▪ Adult grandchild ▪ Adult relative with the closest degree of kinship <p>Note: Different rules apply to emergency room experimental consent</p>	<p>Consent restricted to medical experiments that relate to the cognitive impairment, lack of capacity, or serious, or life threatening diseases and conditions of research participants.</p> <p>This provision N/A to persons involuntarily committed or voluntarily committed by a conservator under the Welfare & Institutions Code</p>	Yes §24178(g)	Consensus needed
Cal. Health & Safety Code §1418.8 (West 2017)	Specialized provision applicable only to nursing homes		<ul style="list-style-type: none"> ▪ Next of kin:” ▪ The attending physician and surgeon in accordance with an interdisciplinary team review 	Applies when “the attending physician and surgeon of a resident in a skilled nursing facility or intermediate care facility prescribes or orders a medical intervention that requires informed consent”	Not addressed	

Default Surrogate Consent Statutes, www.americanbar.org, accessed October 14, 2018

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Cobbs v. Grant

[S.F. No. 22
RALPH CO] A medical doctor, being the expert, appreciates the risks inherent in the procedure he is prescribing, the risks of a decision not to undergo the treatment, and the probability of a successful outcome of the treatment. But once this information has been disclosed, that aspect of the doctor's expert function has been performed. The weighing of these risks against the individual subjective fears and hopes of the patient is not an expert skill. Such evaluation and decision is a nonmedical judgment reserved to the patient alone. [11] A patient should be denied the opportunity to weigh the risks only where it is evident he cannot evaluate the data, as for example, where there is an emergency or the patient is a child or incompetent. For this reason the law provides that in an emergency consent is implied (Wheeler v. Barker (1949) 92 Cal. App. 2d 776, 785 [208 P.2d 68]; Preston v. Hubbell (1948) 87 Cal. App. 2d 53, 57-58 [196 P.2d 113]), and if the patient is a minor or incompetent, the authority to consent is transferred to the patient's legal guardian or closest available relative (Ballard v. Anderson (1971) 4 Cal. 3d 873, 883 [95 Cal. Rptr. 1, 484 P.2d 1345, 42 A.L.R.3d 1392]; Doyle v. Giuliucci (1965) 62 Cal. 2d 606 43 Cal. Rptr. 697, 401 P.2d 1]; Bonner v. Moran (1941) 126 F.2d 121 [75 App.D.C. 156, 139 A.L.R. 1366]). In all cases other than the foregoing, the decision whether or not to undertake treatment is vested in the party most directly affected: the patient.

In Bank. (O
JJ., concurr
COUNSEL
McNamara,
Appellant.
Bonne, Jon
& Prince, R
Leighton M
Mitchell & C
Hassard, B
L. Lamb, La
Boyle & Pop
Curiae on behalf of Defendant and Appellant.

Decision Makers for MEDICAL TREATMENT OF ADULTS

(Special rules apply to mental health commitment, convulsive therapy, psychosurgery, sterilization, abortion and experimental treatment)

Person who can consent to treatment	Definition
<i>The following hierarchy must be followed:</i>	
1. Adult patient with capacity	Able to understand the nature and consequences of the decision; adult is a person age 18 or older
2. Surrogate decision maker	Oral or written appointment by the patient, for duration of stay or illness; maximum 60 days

Person who can consent to treatment

Definition

The following hierarchy must be followed:

1. Adult patient with capacity	Able to understand the nature and consequences of the decision; adult is a person age 18 or older
2. Surrogate decision maker	Oral or written appointment by the patient, for duration of stay or illness; maximum 60 days
3. Agent	Appointed in an Advance Health Care Directive or Power of Attorney for Health Care
4. Conservator	Appointed by a court
5. Court-appointed surrogate decision maker	Court appoints a surrogate to make health care decisions
6. Closest available relative	See “Closest Available Relative” table, below
7. Interdisciplinary team	See “Adults Lacking Capacity and Not Under a Conservatorship” in CHA’s Consent Manual for important information

		8. An adult who exhibited special care and concern for the decedent during the decedent’s lifetime 9. Guardian or conservator of the decedent at the time of death 10. Any other person authorized to dispose of the remains of the unclaimed dead provided that reasonable effort has been made to locate and inform persons listed above	8. Conservator of estate 9. Public administrator, if the patient has assets
	Reference: Health and Safety Code Section 7113	Reference: Health and Safety Code Section 7150.40	Reference: Health and Safety Code Section 7100
*For general medical decisions, case law (not a statute) authorizes decisions by the “closest available relative” and there is no specific hierarchy/order given. It is wise to select the person who seems most familiar with the patient’s values, demonstrates concern for the patient, had regular contact prior to the illness, is available to visit and make decisions, and is able to understand the information and engage in meaningful contact. Agreement with the doctor’s recommendations is not a proper criterion for selection.			

03/17



See chapter 3, “Who May Consent for Adults Lacking Capacity,” of CHA’s Consent Manual for additional information.
See chapter 14, “Deaths, Autopsies and Anatomical Gifts” of CHA’s Consent Manual for additional information regarding autopsies, anatomical gifts, and disposition of remains.
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Decision Makers for MEDICAL TREATMENT OF ADULTS

(Special rules apply to mental health commitment, convulsive therapy, psychosurgery, sterilization, abortion and experimental treatment)

Person who can consent to treatment

Definition

The following hierarchy must be followed:

1. Adult patient with capacity	1. Adult patient with capacity
2. Surrogate decision maker	2. Surrogate decision maker
3. Agent	3. Agent
4. Conservator	4. Conservator
5. Court-appointed surrogate decision maker	5. Court-appointed surrogate decision maker
6. Closest available relative	6. Closest available relative
7. Interdisciplinary team	7. Interdisciplinary team

Surrogate decision maker When a patient's decision maker cannot be contacted, treatment may proceed by

Closest Available Relative

Health Care Decisions	Autopsy
<i>No statutory hierarchy¹</i>	<i>No statutory</i>
<ul style="list-style-type: none"> Spouse/domestic partner Adult child Either parent Adult sibling Grandparent Adult aunt/uncle Adult niece/nephew 	<ul style="list-style-type: none"> Spouse/do Adult chil Adult sibli Any other to control Public adm Coroner or California
	Reference: Hea

¹For general medical decisions, case law (not a statute) authorizes decisions by the "closest available relative" and there is no specific hierarchy/order given. It is wise to select the person who seems most familiar with the patient's values, demonstrates concern for the patient, had regular contact prior to the illness, is available to visit and make decisions, and is able to understand the information and engage in meaningful contact. Agreement with the doctor's recommendations is not a proper criterion for selection.

Health Care Decisions

No statutory hierarchy¹

- Spouse/domestic partner
- Adult child
- Either parent
- Adult sibling
- Grandparent
- Adult aunt/uncle
- Adult niece/nephew

person age 18 or older
the decision; adult is a person age 18 or older
Health Care
tion of stay or illness; maximum 60 days

Power of Attorney for Health Care

CHA's Consent Manual for important information

sions
disability, or to alleviate severe pain, and a surrogate decision
not include treatment that has previously been validly refused.

Disposition of Remains Conservatorship in CHA's Consent Manual for important information

- | | |
|------------------------------|---|
| gift | 1. An agent named in an advance directive |
| | 2. Spouse/domestic partner |
| | 3. Adult child or majority of children |
| | 4. Parent |
| | 5. Adult sibling or majority of siblings |
| | 6. Surviving adults in degree of kinship or a majority of the same degree |
| n for the | 7. Conservator of person |
| ime of | 8. Conservator of estate |
| emains of
ort has
bove | 9. Public administrator, if the patient has assets |

Reference: Health and Safety Code Section 7100

Who is the Unrepresented Patient?

- Moral representation
- Legal representation
- Willing representation



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Moral Representation

Legal Representation

No Legal
Representation

No Moral Representation



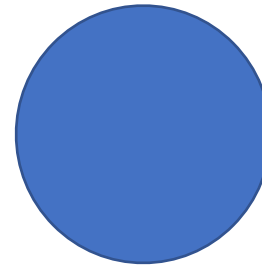
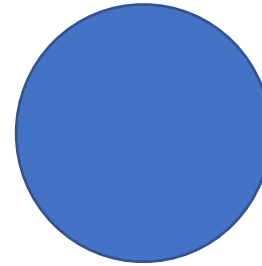
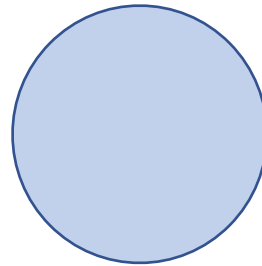
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Moral Representation

Legal Representation

No Legal
Representation

No Moral Representation



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Who is the Unrepresented Patient?

- Can friends make medical decisions for patients?
 - Friends do not have legal authority but have moral authority
- Should the medical team try to find contact information for the estranged son for medical decision making?
 - Yes, but...
 - Ensure surrogate focuses on making decisions that are consistent with the patient's lived and stated values



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Who is the Unrepresented Patient?

- What constitutes an adequate search for a surrogate decision maker?
 - California probate code 4717
 - Examine any available personal effects, accompanying medical records
 - Contact or attempt to contact any agent, surrogate, family members, or other person who can serve as a surrogate
 - Attempt to find the patient's advance directive



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Who is the Unrepresented Patient?

- What constitutes an adequate search for a surrogate decision maker?
 - Search of personal belongings
 - EMR
 - Records from referring facilities
 - Records from primary physician
 - Neighbors



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Who is the Unrepresented Patient?

- Is a surrogate only needed to provide consent or is a surrogate needed to direct (“non-consentable”) medical care?
 - Surrogate should do both
- Who should direct the course of medical treatment? Should it include withdrawal of life sustaining treatment?
 - Multidisciplinary input
 - Avoid tendency towards overtreatment and undertreatment because of lack of patient advocacy and accountability



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Unrepresented Patient Policy Needs

- Easily identify the patients who would benefit
- Fulfill the legal requirement of providing consent
- Fulfill the moral requirement of providing direction consistent with what is known about the patient



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Unrepresented Patient Policy Needs

- Provide clinical staff with an easy to follow workflow
- Facilitate prompt and appropriate medical treatment
- Build in accountability for just and equitable decision making for a vulnerable population



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ROI Analysis

- US Census Bureau projection released in 2012
 - Population > 65 years old will more than double between 2012 and 2060
 - 43.1 million to 92 million
 - In 2060, 1 in 5 persons
 - Population > 85 years old will more than triple between 2012 and 2060
 - 5.9 million to 18.2 million
 - In 2060, 4.3% of the total population

<https://www.census.gov/newsroom/releases/archives/population/cb12-243.html>, accessed 10/14/18



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ROI Analysis

- 3-4% of nursing home residents
 - Incapacitated and Alone: Healthcare Decision Making for the Unbefriended Elderly, https://www.americanbar.org/content/dam/aba/administrative/law_aging/2003_Unbefriended_Elderly_Health_Care_Descision-Making7-11-03.authcheckdam.pdf , accessed 10/14/18
- Multicenter study of 7 ICUs → unrepresented patients made up 5.5% of deaths in the ICU
 - Ranged from 0-27% across 7 centers
 - White, *Ann Intern Med*, 2007



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Identifying the Institution's Responsibility

- Promote and support ethical clinical decision making for vulnerable populations
 - Consistent with institutional values
- Equitable distribution of capitated healthcare dollars
 - Avoid overtreatment and undertreatment
- Institution risk assessment and management
 - Interdisciplinary team model of decision making borrowed from California statute authorizing medical decision making for unrepresented patient residing in nursing homes



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Identifying the Institution's Responsibility

- CANHR v. Chapman
 - California Advocates for Nursing Home Reform - advocacy group for long term care residents
 - Lawsuit to stop the use of interdisciplinary teams (IDT) in nursing homes to make medical decisions for unrepresented patients
 - Alameda County Superior Court ruled that California Health and Safety code 1418.8 violates California's constitution because patients were not informed of:
 - Unrepresented status
 - Medical decisions were being made on their behalf
 - How to seek judicial review



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Identifying the Institution's Responsibility

- CANHR v. Chapman
 - Also prohibits use of IDT to authorize administration of antipsychotic drugs or end-of-life treatment
 - Ruling is not currently in effect, pending appeal
- Establishment of a conservator for patients without a psychiatric diagnosis requires ~ 3 months



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Identifying the Institution's Responsibility

- California Probate Code, Healthcare Decisions Act

4650. The Legislature finds the following:

- (a) In recognition of the dignity and privacy a person has a right to expect, the law recognizes that an adult has the fundamental right to control the decisions relating to his or her own health care, including the decision to have life-sustaining treatment withheld or withdrawn.
- (b) Modern medical technology has made possible the artificial prolongation of human life beyond natural limits. In the interest of protecting individual autonomy, this prolongation of the process of dying for a person for whom continued health care does not improve the prognosis for recovery may violate patient dignity and cause unnecessary pain and suffering, while providing nothing medically necessary or beneficial to the person.
- (c) In the absence of controversy, a court is normally not the proper forum in which to make health care decisions, including decisions regarding life-sustaining treatment.

(Added by Stats. 1999, Ch. 658, Sec. 39. Effective January 1, 2000. Operative July 1, 2000, by Sec. 43 of Ch. 658.)



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Policy Development

- CHA model policy for unrepresented patients as a starting point
- Input from various stakeholders
- Committee approval process
- Approved and went into effect June 2016
- Educational efforts
 - QI meetings
 - Individual department education
 - Grand Rounds presentations



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Final Policy

- Multidisciplinary committee format
 - Inclusion of those with moral authority
 - Community member
- Triggered by required decision regarding medical treatment or a procedure that requires consent
 - MD/DO, RN, SW, CM or multidisciplinary rounds
- Physicians should provide the committee with the same information regarding diagnosis, prognosis, and risks / benefits of any proposed procedure as they would to the patient and/or family



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Final Policy

- Discussion open to all participants
 - Guided by ethics consultant
- Agreement by all for treatment decisions
 - Including withdrawal of life sustaining treatment
- If there is disagreement:
 - Current therapy is continued
 - Ad-hoc meeting with members of the hospital ethics committee
 - Meeting of the full hospital ethics committee
 - Court imposed legal remedies



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Final Policy

- The following procedures cannot be authorized under this policy:
 - Autopsies, anatomical gifts, or disposition of remains
 - Pregnancy termination
 - Primary sterilization



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Guiding the Discussion

- Gather and use all sources of information
 - Learn about the patient (become a friend)
 - Ask about goals and values, cultural or religious beliefs
- Practice good medicine
 - Diagnosis - how sure are we of the diagnosis?
 - Reversibility / Recovery - what would it take to bring the patient back to his pre-morbid state?
 - Prognosis - ensure appropriate workup has been done to verify projected outcome
 - Adequate relief of pain and suffering throughout process



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Guiding the Discussion

- Identify biases that can affect decision making
 - Ageism - focus on pre-morbid functional status instead of age
 - Search satisfaction bias - have all avenues of patient information been exhausted?
 - Confirmation bias - are we considering all the information available?
 - Bandwagon or groupthink effect - are behaving like intellectual lemmings?
 - Diagnosis momentum - is the diagnosis sticky because it is true or because it has been repeated over and over again?



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Guiding the Discussion

- Identify biases that can affect decision making (con't)
 - Authority bias - empowering all present to ask clarifying question and voice concerns
 - Cognitive miser bias - are we choosing the treatment path that requires the least amount of cognitive energy?
 - Stereotyping - is our discussion being shaped by societal expectations based on the patient's gender or ethnicity



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Guiding the Discussion

- Identify biases that can affect decision making (con't)
 - Information bias - how will the additional information affect our decision making process?
 - Able-bodied bias - how do we know the patient is experiencing a poor quality of life?
 - Overconfidence bias - is our recommendation based on opinion or fact?
 - Money - are there monetary considerations that should be discussed?
- Consider ways in which to counteract negative influence of identified biases



Guiding the Discussion

- Discuss risks / benefits of treatment options
- Plan for the future
 - What additional decisions will need to be made during this hospitalization?
 - How will changes in the medical team affect this patient's care?
 - Apply for conservatorship, if needed
- All decisions only apply during this hospitalization



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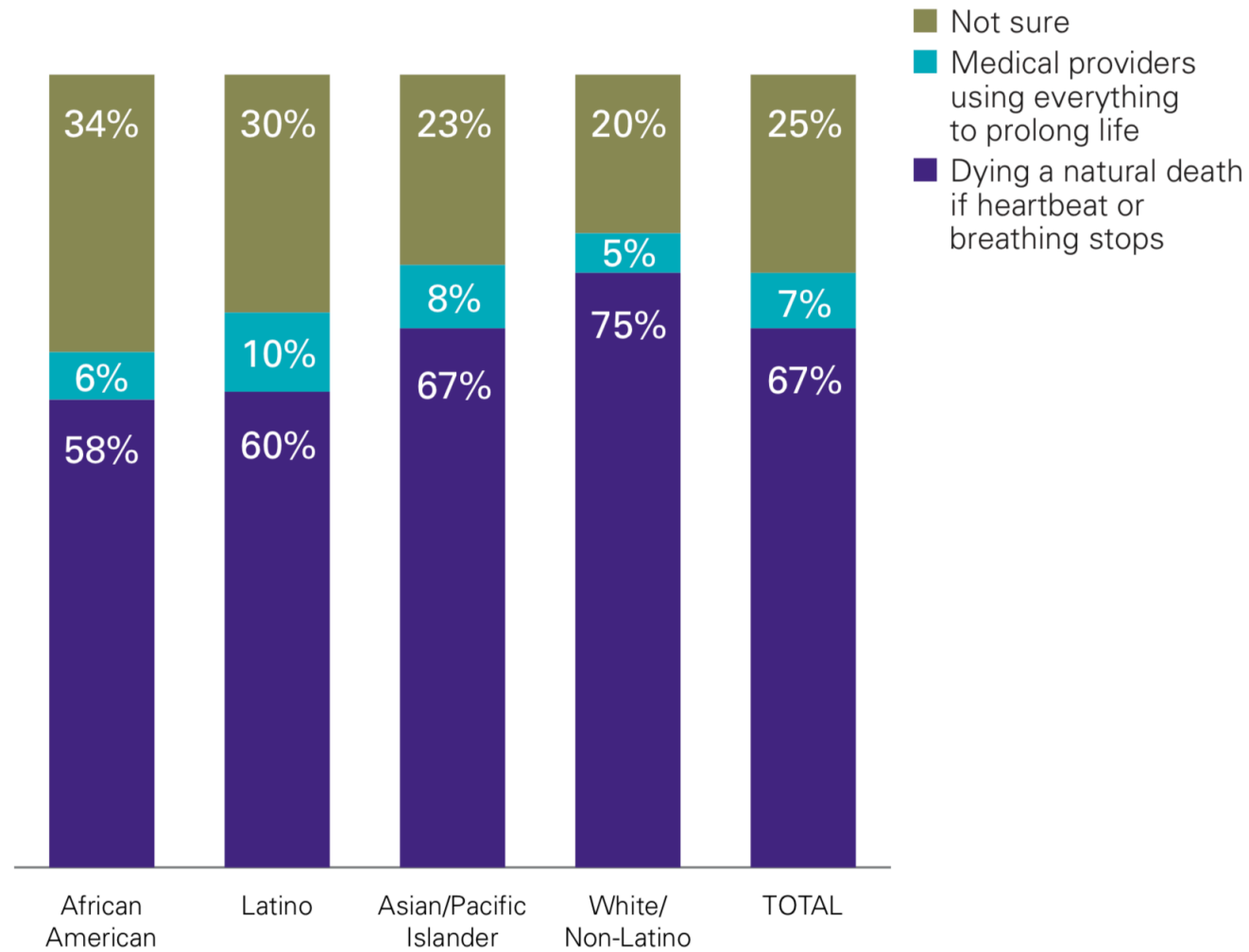
Philosophical Objections

- What is the philosophical basis for decision making, including withdrawal of support in the absence of any known patient preference?
 - Best interest standard
 - Commonly held community values rated extremely important at the end of life
 - Relief of pain and suffering - 66%
 - Being at peace spiritually - 61%
 - Living as long as possible - 36%



Philosophical Objections

Preferences Around Prolonging Life,
by Race/Ethnicity, California, 2011



Final Chapter: Californians' Attitudes and Experiences with Death and Dying, 2012

Philosophical Objections

- What is the philosophical basis for decision making, including withdrawal of support in the absence of any known patient preference?
 - Best interest standard
 - Commonly held community values around end of life care
 - **Patient centered ethic of caring**



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Philosophical Objections

- Who is the patient's advocate against the health system?
 - Start with the intention of *befriending* the patient and embedding the patient as part of our community
 - Correct for bias as much as possible
 - Include community member in discussion
 - Accountability through weekly peer review at ethics case conference and monthly committee review at institutional Ethics Committee



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Philosophical Objections

- But what if the multidisciplinary committee is “stacked” towards a certain outcome?
 - Ensure participation of clinicians actively caring for the patient
 - Recognition of biases
 - Focus on process, not outcome
 - Recognize the patient as “one of us”, not as “other”



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Philosophical Objections

- How do you balance the patient's interest and the institution's interest in allocating / distributing resources?
 - Policy was crafted and intended to benefit the *individual* patient
 - If resource allocation is an issue, institutional benefit should be openly and honestly discussed
 - Institutional benefit derives from clinician / employee buy-in to provide excellent care through an honest and transparent process



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Philosophical Objections

- Does this policy take autonomy away from the responsible physician?
 - No - this policy enhances physician accountability by requiring a transparent process of decision making
 - No - this process requires physicians to come to the discussion prepared to recommend a course of treatment
 - Provides a process for concerns from non-physician disciplines to be openly discussed
 - Implementation of recommendations to withdraw life-sustaining treatment is up to the responsible clinician



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Practical Objections

- Are clinicians trained to take part in this process? How good is the process if the clinicians don't know how to do it?
 - Clinical ethics consultant guides discussion
 - Clinicians should come prepared with information similar to what would be presented to the patient's family



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Practical Objections

- It's too slow and cumbersome
 - Most multidisciplinary meetings occur within 24 hours of request (even on weekends)
 - Delay can occur because the responsible clinician fails to recognize the need for a multidisciplinary meeting



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Practical Objections

- It's too much work for some easy decisions that require consent - i.e. discharge to a skilled nursing facility
 - Working on a list of low risk decisions that a clinician can make without requiring a multidisciplinary meeting through Ethics Committee



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Practical Objections

- If life sustaining treatment is withdrawn, do patients die alone?
 - No One Dies Alone volunteer program
 - Chaplain provide spiritual support



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Accountability

- 2016 - approved
- 2017 - 31% of clinical ethics consults
- 2018 - YTD 38% of clinical ethics consults
 - 53% - continuation of medical therapy
 - 25% - withdrawal of life sustaining treatment
 - 19% - limitation of treatment, transition to hospice

How Are We Doing?

Mr. Diaz, 70 year old unrepresented male

- Admitted from a skilled nursing facility with septic shock from severe C. difficile colitis
- Emergently intubated and brought to the OR for colectomy
- No apparent next of kin
- Friend's phone number found amongst belongings
- Ethics consult for multidisciplinary meeting the same day



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How Are We Doing?

Mr. Diaz, 70 year old unrepresented male

- POLST from outside SNF listed full code, full treatment
- No advance directive, no durable power of attorney



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How Are We Doing?

Mr. Diaz, 70 year old unrepresented male

- Spoke with friend (who could not come to the meeting) and obtained history about the patient
- No family in the US
- Previously healthy, worked in landscaping, rented a room in a house where 4 other people lived
- Contracted C. difficile colitis → treated at an outside hospital → discharged to rehabilitation unit of SNF → intention was to get better



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How Are We Doing?

Mr. Diaz, 70 year old unrepresented male

- Clinical condition
 - Open abdomen with wound vac, in DIC
 - Previously on two vasopressor agents but now down to one
 - Previously required multiple blood component transfusions but need has decreased
 - Responding to commands when sedation decreased
 - Surgery would like to go back for a second look



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How Are We Doing?

Mr. Diaz, 70 year old unrepresented male

- Reasonable expectation of reversing this condition
- Improving clinically
- Baseline healthy and independent prior to C. difficile infection
- Continue aggressive therapy, authorize surgical intervention, continue to follow



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How Are We Doing?

Mr. Diaz, 70 year old unrepresented male

- Two days later develops multisystem organ failure, likely from a superimposed infection
- Higher level of support than after emergency colectomy
- No longer neurologically responsive
 - Too unstable for brain imaging
- Team does not have a reasonable expectation of reversibility



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How Are We Doing?

Mr. Diaz, 70 year old unrepresented male

- DNAR, limitation of support if burden exceeds benefit
- Life sustaining treatment was not withdrawn
- Mr. Diaz died a few hours later in the ICU



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How Are We Doing?

- Easily identify the patients who would benefit
- Fulfill the legal requirement of providing consent
- Fulfill the moral requirement of providing direction consistent with what is known about the patient



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How Are We Doing?

- Provide clinical staff with an easy to follow workflow
- Facilitate prompt and appropriate medical treatment
- Build in accountability for just and equitable decision making for a vulnerable population



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Conclusions

- Process is better than no process at all
 - More transparent
 - Allows for institutional and individual reflection
- Process is only as good as the medical treatment
 - Ethics cannot salvage the poor practice of medicine
- Process requires individual and collective accountability
 - Ongoing refinement of policy



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Questions?
Thank you